

[Disability Home](#)SSA
logo:
[Link to](#)

Disability Notes

In this Issue:

[Associate
Commissioner's Message](#)[New Packet to Help In
Applying For SSI
Disability Benefits for
Children](#)[Collaborative Initiative To
Assist Minority Families of
Children With Disabilities](#)[New Internet Guide Helps
People Complete
Disability Form](#)[Medicare and You 2002](#)[You Can Avoid
Overpayments](#)[SSA Awards Cooperative
Agreements and Grants
Under the Ticket to Work
Legislation](#)[SSI Trusts](#)[Regulations to Insure
Privacy of Health Care
Records](#)**Pub No. 64-040 Issue 3-2001 (No. 30)**[PDF](#)

Disability Notes is informational only and not an official expression of policy.

[Return to Disability Notes Main Page](#)

FROM THE ASSOCIATE COMMISSIONER:

The tragic events of September 11th inflicted loss of precious innocent life, and pain and suffering to many. Both individually and collectively we need to defend and reaffirm the national values threatened by such wanton acts.

Social Security, together with other government and non-government agencies, is providing assistance to the survivors and with the recovery. The many public servants that work to bring the Social Security programs to you are reaching even deeper into their hearts and souls being more mindful of our collective role in securing the values of this great nation. The following link provides more information on what SSA is doing to help. <http://www.ssa.gov/emergency.htm>.

In this issue of Disability Notes, we update you on a broad range of activities in the disability program. The articles on a new information packet we designed to help parents and other individuals who are applying for SSI benefits for a disabled child and our collaborative initiative to assist minority families of children with disabilities reflect our commitment to children with severe disabilities. Articles on our Internet guide to help complete a key form in the application process, the new Medicare and You publication and the training kit for representative payees provide current useful information. We inform you on our work with the Surgeon General to develop an action agenda to address the unique health care needs of children and adults with mental retardation.

We also update you on some key activities in the implementation of the Ticket to Work law and the regulations to insure privacy of health records. There are also informative articles on SSI Trusts and preventing overpayments.

These articles highlight just some of our efforts to ensure that the disability

[Recruiting and Training
Kit for Representative
Payees](#)

[National Meeting on
Health and Health Care
Needs of Individuals with
Mental Retardation](#)

EDITOR'S NOTES:

In Search of your Ideas and Materials

This newsletter is your newsletter. We welcome your articles, letters to the editor, comments or suggestions for improvement. Many of your ideas have been included in recent issues.

Subscription

Disability Notes is free of charge to readers interested in the disability program. You can get all new issues on this web site. If you prefer to get a copy by E-mail or post office mail, please send your request to:

Julian Manelli, Editor
Social Security
Administration
Office of Disability
Programs
Room 4512 Annex
Building
Baltimore, MD 21235

programs will continue to serve the needs of the nation. I hope you will find this issue informative.

Ken Nibali

NEW PACKET TO HELP IN APPLYING FOR SSI DISABILITY BENEFITS FOR CHILDREN

Early this fall we provided the field offices and teleservice centers with a new packet to help individuals to apply for SSI disability benefits for children. The packet is designed to give parents or other individuals who are applying on behalf of a child information and forms to assist with the application process. Some of the information in the packet is available on our web site, <http://www.ssa.gov/about.htm>

The packet, which comes in a handy 9"x12" envelope that can also be used for holding papers, contains the following:

- A pink instruction sheet, "How to Use This Packet," which lists the information in the envelope.
- A four-page factsheet, "Facts About SSI for Children with Disabilities," which summarizes information for qualifying for SSI childhood disability benefits.
- A pamphlet titled, "Benefits for Children with Disabilities," (SSA Pub. No. 05-10026). This publication discusses both the medical and nonmedical requirements for qualifying for SSI childhood disability benefits.
- A pamphlet titled "Supplemental Security Income," (SSA Pub. No. 05-11000). This publication explains the overall program
- One copy of the form, "Disability Report-Child", SSA-3820-BK. The questions on this form help us gather information about the child's disabling condition.
- Seven copies of the form, "Authorization for Source to Release Information" (SSA-827-OP2). By signing this release form, you give permission to the individuals and organizations that have information about the child's condition to release that information to us.

COLLABORATIVE INITIATIVE TO ASSIST MINORITY FAMILIES OF CHILDREN WITH DISABILITIES

This collaborative initiative is funded by four federal partners: the Social Security Administration, the Administration on Developmental Disabilities, the Centers for

Telephone (410) 965-9022

FAX (410) 965-4054

Julian.A.Manelli@ssa.gov

Medicare and Medicaid Services (formerly the Health Care Financing Administration) and the Office of Child Support Enforcement. The Human Services Research Institute of Salem, Oregon was contracted to fund eight sites nationally to carry out the work and will offer the eight project sites technical assistance.

The purpose and goal of each site is to create opportunities for minority families of children with disabilities to apply for and utilize needed services. Each project is expected to engage local stakeholders, including minority families, existing community organizations and federal, state and local officials to fashion innovative opportunities for minority families to apply for and utilize needed services.

This effort encourages partnerships between SSA and the other federal agencies and the community to reach eligible minority families of children with disabilities--among the more vulnerable of our citizens.

NEW INTERNET GUIDE HELPS PEOPLE COMPLETE DISABILITY FORM)

Last year a little over three million individuals filed application for benefits under one of the disability programs administered by SSA. Nearly all the applicants needed to provide information to complete the Disability Report Form for Adults (SSA-3368).

A new Internet tool provides online help and explanations in completing the form, making it easier for adults to file for disability benefits. The form helps SSA obtain information about an applicant's condition and how it affects him or her. It also provides us with information about medical and other sources of information that we use to get evidence for the claim. If you want to file for adult disability benefits, don't delay--call the SSA toll free number, 1-800-772-1213, or contact your local SSA office.

While claims representatives in SSA's local offices help applicants complete the Disability Report Form for Adults (SSA-3368), it is best for individuals to have as much of the form completed as possible before the interview.

With the new online tool applicants and individuals assisting applicants can get online help. By a mouse click on any section of the online form, the applicant will receive a 'plain language' explanation of what information is needed, why we need the information and how answers will help us in making a disability decision. There is no question that applicants who complete the form thoroughly find the disability interview easier. The information on the form makes the claims process a lot smoother and problem-free.

To get started in completing the form or to just simply look it over go to:
<http://www.ssa.gov/disabilityformhelp>

MEDICARE AND YOU 2002

More than 38 million Medicare beneficiaries nationwide will find the latest Medicare information in their mailboxes. The new Medicare handbook, Medicare and You 2002, should have arrived at all beneficiary households between September 15 and October 15 of this year.

The handbook contains basic information on Medicare, including covered services, enrollment, rights, health plan options, supplemental insurance, help with health care costs and phone numbers for more information.

The handbook explains coverage and services that are new this year, including:

- Glaucoma screening
- Clinical trials
- Treatment for macular degeneration
- Medical nutrition therapy
- New rules for joining and leaving health plans
- Immunosuppressive drug coverage
- Medicare Personal Plan Finder
- Expanded telephone service

If you have Medicare and didn't receive a copy of Medicare and You 2002, or you need an additional copy, call 1-800-MEDICAR (1-800-633-4227) or visit <http://www.medicare.gov> on the Internet.

YOU CAN AVOID OVERPAYMENTS

If you're a Social Security disability beneficiary who works, you'll want to avoid overpayments. And the way to do that is to report any work you do promptly. Be sure to let us know if you start or stop working, if your health improves or if your earnings increase or decrease.

Nobody wants to worry about returning money already spent, especially people who depend on their disability benefits. But delay in providing information about work you do or improvements in your health can lead to incorrect payments that you may have to repay.

For example, it's important to let us know if you return to work, even if your earnings are small. Most Social Security disability beneficiaries are entitled to a 9-month trial work period that allows them to work and earn any amount of money without affecting the amount of their benefits. The nine trial work months don't need to be consecutive. They can be spread out over five years. In 2001, any month that you earn \$530 or more counts as one of the trial work months.

If you complete nine trial work months and you have a disabling condition, we look at your earnings after that to see if you are working at a "substantial" level - usually \$740 or more a month. If so, your benefits stop. However, even if your

regular monthly benefits cease, you may still be entitled to benefit payments for any month that your earnings fall below \$740. And if you are still disabled, your Medicare can continue for at least 39 months after your trial work period ends.

Be sure to let SSA know right away if your earnings drop, or if you're unable to continue working because of your disability. That's the best way to help us make sure that you get all the benefits you're entitled to.

SSA will not make any adjustments to your monthly benefits without advance notice. You will be notified about any changes in your entitlement to benefits. And you always have the opportunity to appeal any decision we make and to give SSA more information about your situation.

The pamphlet, *Working While Disabled - How We Can Help* (Pub. 05-10095), provides you with more details and information. You can order a free copy by calling 1-800-772-1213 or you can access it on the web:

<http://www.ssa.gov/work/ResourcesToolkit/>

SSA AWARDS COOPERATIVE AGREEMENTS AND GRANTS UNDER THE TICKET TO WORK LEGISLATION

As required by The Ticket to Work and Work Incentives Improvement Act (TWWIIA) of 1999, SSA established a total of 117 community-based Benefits Planning, Assistance and Outreach (BPAO) projects in every state, the District of Columbia and the US territories of American Samoa, Guam, the Northern Mariana Islands, Puerto Rico and the US Virgin Islands. SSA was required to make awards based on the population of SSDI & SSI beneficiaries with disabilities who could be served by the projects. The BPAO projects are expected to be funded through FY 2004.

To this end, SSA solicited applications from state and local government agencies, public and private organizations and nonprofit and for-profit organizations to disseminate timely, accurate information to SSA beneficiaries with disabilities (including transition-to-work-aged youth) about work incentives programs and issues related to such programs. The intent is for all SSA disability beneficiaries to have access to benefits planning and assistance services from non-SSA Benefits Specialists. The goal of the Benefits Planning, Assistance and Outreach (BPAO) Program is to better enable SSA's beneficiaries with disabilities to make informed choices about work.

The responsibilities of the BPAO Program Benefits Specialists are to:

- Provide work incentives planning and assistance to SSA's beneficiaries with disabilities;
- Conduct outreach efforts to those beneficiaries (and their families), who are potentially eligible to participate in Federal or State work incentives programs; and
- Work in cooperation with Federal, State and private agencies and

nonprofit organizations that serve beneficiaries with disabilities.

The 1999 legislation also created a new Protection and Advocacy (P&A) Program known as Protection and Advocacy for Beneficiaries of Social Security (PABSS) to serve SSDI and SSI beneficiaries who want to work despite their continuing disabilities. The purpose of the program is to provide P&A services that SSDI and SSI beneficiaries may need to secure or regain gainful employment. This includes: 1) information and advice about obtaining vocational rehabilitation and employment services and 2) advocacy or other services that a beneficiary with a disability may need to secure or regain gainful employment.

The P&A system is a system of disability-related advocacy services that is available, free of charge, in every state. Each state has a designated state P&A agency that has the capacity to provide a wide range of advocacy services to persons with disabilities through several specific P&A grants.

SSA contracted with the Cornell University, Virginia Commonwealth University, and the University of Missouri-Columbia, to develop and provide technical assistance and training to all BPAO Benefits Specialists and P&A agencies on SSA's disability programs and work incentives, the Medicare and Medicaid programs and on other Federal programs. BPAO Program awardees must provide training and technical assistance to their Benefits Specialists about their own State and local programs and their effects on other programs' eligibility and benefits.

SSA also entered into a contract with the National Association of Protection and Advocacy Systems (NAPAS) to provide technical assistance on administrative, systems and management issues to the P&As. BPAOs are required to provide beneficiaries information concerning the availability of P&A services and how to access such services.

For more information about the BPAO Program or the PABSS Program, visit our web site at <http://www.ssa.gov/work/ServiceProviders/congrant2.html>.

SSI TRUSTS

At a disability advocate meeting, I was approached by aging parents of a child with a severe disability with this question: "I want to set up an SSI Trust for our child. Would you tell me about SSI Trusts and whether we should set one up?"

While SSA cannot provide advice on whether an individual should create an SSI Trust we can provide information about SSI Trusts.

Trusts are a complicated and confusing subject, but in certain situations a trust can give an SSI beneficiary more financial independence. A trust is a legal arrangement regulated by State law in which one party holds property for the benefit of another. A trust can contain cash or other liquid assets and/or real or personal property. For SSI purposes, property in a trust may or may not be

considered a resource. The SSI resource limits are \$2,000 for an individual and \$3,000 for a couple.

Since January 1, 2000, when a recipient uses his or her assets to establish a trust, we may count all or part of the trust as a "resource." In the case of a revocable trust, the whole trust is considered a resource. For an irrevocable trust, if there are any circumstances under which payment could be made to a recipient for his or her benefit, the portion of the trust from which payment could be made is counted as a resource. Several types of trusts are legally excluded from resources, including special needs trusts established for disabled persons under 65, pooled trusts and trusts established under the terms of a will. In addition, the Commissioner may waive counting a trust as a resource if it would cause undue hardship on the individual.

A trust established for an individual with a third party's assets is a resource to an individual who has an ownership interest in the trust and the legal authority to revoke the trust and then use the funds to meet his or her food, clothing or shelter needs or to an individual who can direct the use of the trust principal for support and maintenance under the terms of the trust. However, if an individual cannot revoke the trust or direct use of the trust principle for support and maintenance, the trust is not considered a resource for SSI purposes. Money from this type of trust that is paid to a third party to provide a beneficiary with food, clothing or shelter is considered in-kind support and maintenance and will reduce a beneficiary's SSI payment. It should be noted however that no matter how much is spent for these items, no more than \$197 (in 2001) can be subtracted from the SSI payment in the month the items are received. Money from the trust that is paid directly to a third party that result in the beneficiary receiving items that are not food, clothing or shelter are not considered income for SSI purposes. For example, if trust funds are paid to a provider of medical services for care rendered to a beneficiary, the payments are not considered income.

Trust earnings are not counted as income for an SSI recipient who is a trust beneficiary unless the trust directs, or the trustee makes, payments to the beneficiary. However, certain payments are non-assignable by law and, therefore, are counted as income to the individual. Non-assignable payments include:

- Temporary Assistance to Needy Families (TANF);
- Railroad Retirement Board-administered pensions;
- Veterans pensions and assistance;
- Federal employee retirement payments (CSRS, FERS) administered by OPM
- Social Security and SSI payments; and
- Private pensions under the Employee Retirement Income Security Act (ERISA).

Individuals who are interested in setting up a trust should contact a lawyer or financial advisor. The Social Security administration cannot give advice on how to set up a trust.

REGULATIONS TO INSURE PRIVACY OF HEALTH CARE RECORDS

In the course of processing disability applications and claims reviews, SSA request that individuals sign releases, Authorization for Source To Release Information to the Social Security Administration (SSA Form 827), so that health care information can be secured from their health care providers. Health care providers require that signed releases are secured from their patients before any health information is shared. Ensuring privacy of medical records has been a primary concern of both SSA and the health care community. New regulations will further the proper use and disclosure of health information.

Earlier this year regulations were issued by the Department of Health Human Services (HHS) which serves to strengthen the privacy of medical records. The regulations were a result of the Health Insurance Portability and Accountability Act (HIPAA) of 1996. That legislation addressed a wide range of health care issues included privacy of medical records and standards for the electronic transmission of personal health information. The Congress recognized the need for national patient privacy standards in light of changing technology on how health records were being stored and transmitted.

The regulations and guidelines are available on the web at <http://www.hhs.gov/ocr/hipaa> . This site provides answers to common questions about the new protection for consumers and requirements for doctors, hospitals, other providers, health plans, health insurers and health care clearinghouses. The regulations cover the electronic transfer of records, the privacy and security of paper documents and oral communications about health related matters. Here are key issues covered by the regulations:

- Specific criteria for a valid authorization for disclose health information
- New criminal and civil sanctions for improper use or disclosure by a covered entity
- New rights for individuals to access their own medical records and to know who else has accessed their records
- A "minimum necessary" standard for disclosures made without an authorization
- Limit on the non-consensual use and release of private health information
- Specific rules for access to records for research and other specific public purposes

The regulations became effective April 14, unless further modified. All entities covered in the regulations must comply by April 14, 2003. HHS' Office for Civil Rights will conduct extensive outreach to consumers and healthcare providers to explain what the rules mean for them. HHS also will provide technical assistance and further guidance to healthcare providers and other covered entities to help

them comply.

SSA and the health care community are working to implement these regulations. SSA is committed to the implementation of the regulations and the proper use and disclosure of health care information.

RECRUITING AND TRAINING KIT FOR REPRESENTATIVE PAYEES

SSA's Representative Payment Program provides fiduciary assistance for our beneficiaries who are incapable of managing or directing someone else to manage their Social Security or SSI payments. Generally, we look for family or friends to serve in this capacity. When friends and family are not able to serve as payee, SSA looks for qualified organizations to be a representative payee. SSA's Office of Program Benefits has produced two valuable training kits to recruit and train organizations that wish to become representative payees. Here is what the kits contain:

The recruitment kit includes a recruitment video, a fact sheet and talking points that discuss the benefits of this important program.

The training kit includes a training video, a lesson plan, handouts and a guide for organizational payees.

These kits will also be available in CD ROM. The kits will be distributed to all SSA field offices in December 2001. Call your local SSA office to arrange a training session when the kits became available.

If you would like information on the representative payment program, please visit our website at <http://www.ssa.gov/payee>. If you would like a copy of the training kit, please send mail.to:organizational.payee.training.campaign@ssa.gov

NATIONAL MEETING ON HEALTH AND HEALTH CARE NEEDS OF INDIVIDUALS WITH MENTAL RETARDATION

SSA has long recognized what a critical factor health care is in the lives of individuals with mental retardation. SSA, together with the Surgeon General and many other federal agencies, is working to convene a major national meeting on the unique health issues of individuals with mental retardation. The meeting, "Health Disparities and Mental Retardation: A Surgeon General's Conference," will be held in Washington D.C. in early December.

One of the major purposes of this event is to focus attention on the unique health care needs of children and adults with mental retardation. The topics to be discussed include: the need to improve health provider education; challenges in diagnosing a range of conditions that often occur, but may go undetected in children and adults with mental retardation; the need to overcome stigma; and ways to improve the quality of and access to health care. Points of agreement and

recommendations from the conference will be summarized in a report that will form the basis for an action agenda.

The Conference will be preceded by a Listening Session both through the web page and in a multi-link session in early October. The goal of this session is to hear directly from all whom are interested in this subject. For more information, the web site is:

<http://www.surgeongeneral.gov/topics/mentalretardation/listeningsession.htm>

[Link to](#)

[Privacy Policy](#) | [Accessibility Policy](#) | [Linking Policy](#) | [Site Map](#)

[Link to](#)